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Motherhood Experiences of Visually Impaired Women – A Feminist Disability Studies Approach

Abstract

It is important to separate disability studies research by gender because women may have different experiences from men. Research on specific situations faced by women, such as motherhood, is particularly important in order to get a broader picture of the oppression of disabled people. In our study, we explored the motherhood experiences of five visually impaired Hungarian women using a feminist disability studies approach. We conducted narrative life history interviews with them. We combined two qualitative research methods, Grounded Theory and narrative life history interviews, to explore aspects of the topic that are hardly accessible and to create a frame of the experiences. We used MAXQDA 2022. Our research focuses on the question: What characterises visually impaired mothers' experience and lived experiences of motherhood? According to our research, fear of passing disability on to their children plays a role in their decision-making process, although there is no ground for exclusion. Visually impaired women also experience obstetric violence. Regarding infant care and parenting, they turn to alternative techniques which they either invent themselves, learn at the particular rehabilitation module *Special Techniques of Infant Care for visually impaired Persons* or from other visually impaired parents. In conclusion, mothers might need alternate solutions, but this is possible.

Keywords: visually impaired women, visually impaired mothers, feminist disability studies, motherhood experiences of visually impaired women

Látássérült nők anyaságélményei – feminista fogyatékosságtudományi megközelítésből

Absztrakt

Tanulmányunkban öt látássérült magyar nő anyasággal kapcsolatos tapasztalatait vizsgáltuk feminista fogyatékosságtudományi szempontból. Narratív élettörténet interjúkat vettünk fel velük. Két kvalitatív kutatási módszert, a Grounded Theory-t és a narratív élettörténet interjút kombináltuk, hogy feltárjuk a téma nehezen hozzáférhető aspektusait, és keretet adjunk a tapasztalatoknak. A MAXQDA 2022 programot használtuk. Kutatásunk a következő kérdésre összpontosít: Mi jellemzi a látássérült anyák tapasztalatait és megélt anyasági élményeit? A fogyatékosság gyermekeikre való átörökítésétől való félelem szerepet játszik a döntési folyamatukban, bár ez nem kizáró ok. A látássérült nők szülészeti erőszakot is tapasztalnak. A csecsemőgondozás és a gyermeknevelés tekintetében alternatív technikákhoz folyamodnak, amelyeket vagy maguk találnak ki, vagy *A csecsemőgondozás speciális technikái látássérült személyek számára* speciális rehabilitációs modulban tanulják meg, vagy más látássérült szülőktől tanulnak. Összefoglalva, az anyasághoz alternatív megoldásokra lehet szükség az életükben.

Kulcsszavak: látássérült nők, látássérült anyák, feminista fogyytékosságtudomány, látássérült nők anyaságélményei

Motherhood Experiences of Visually Impaired Women – A Feminist Disability Studies Approach[1]

1. Introduction: A feminist approach to multiple oppression in disability studies

Multiple oppression is an issue in Disability Studies that has given criticism of the social model of disability. One of the loudest critiques has come from feminist disability studies female researchers, who have been arguing since the 1990s for the need to examine oppressive structures within the intersections of disability and femininity (Meekosha, 2004; Garland-Thomson, 2002; Wendell, 1996). Another criticism is that disability is such a robust identity-forming phenomenon that it takes precedence over other characteristics of the individual (e.g., social gender) and oppresses everything in the eyes of mainstream society. The above mentioned suggest that being a disabled woman is a multiple oppressed situation (Kálmán & Könczei, 2002; Hammer, 2016; Lendvai & Nguyen Luu, 2022). Shakespeare (2006) suggests that the primary task of a qualitative researcher is to investigate the extent and different aspects of oppression. We do the same now by studying and

1 The research was carried out with the research ethics permit issued by the Scientific and Research Ethics Committee of Eötvös Loránd University, Bárczi Gusztáv Faculty of Special Needs Education. The research permit number is KEB/2021/020.

presenting the experiences of visually impaired women. In our study, we focus on the experiences of visually impaired women in relation to motherhood.

2. Disabled mothers

2.1. Ableism and motherhood

We have relatively little data on how many people with disabilities have children (Prónay & Góczán-Szabó, 2020). Most of our data comes from qualitative research in disability studies, special education and psychology, and the intersections of these disciplines (Hernádi & Könczei, 2013; Hernádi, 2014; Wołowicz-Ruszkowska, 2015; Hankó et al., 2022; Katona et al., 2016; Katona & Szücs, 2017, 2018; Lappeteläinen et al., 2016; Lendvai & Nguyen Luu, 2019; Lendvai, 2019, 2022). There are several reasons for this lack of data, all rooted in ableism. Most societies consider disabled people asexual and incompetent, so having children is out of the question. Disabled people might face physical and/or psycho-emotional barriers to sexuality, which further complicates their situation regarding having children (Kálmán & Könczei, 2002; Esmail et al., 2010; Loeser et al., 2017; Santos & Santos, 2017; Zagyi & Csángó, 2019; Bahner, 2022). It can also be caused by people's fear of passing on disability. Women who receive positive genetic test results during their pregnancy are often advised to abort their supposed "not healthy" fetus or leave the baby at the hospital (Hernádi & Kunt, 2018). This is also a fear of the cultural reproduction of disability. These are the recognizable and less apparent signs of ableism. We will discuss this issue in more detail later in our paper. Women often experience a particular kind of violence, obstetric violence, and disabled women are particularly vulnerable in this matter (Diaz-Tello, 2016; Kertész & Nyúl, 2022; Sadler et al., 2016; Wudneh et al., 2022; Lendvai & Nguyen Luu, 2019, 2022; YupanquiConcha et al., 2024).

What does being a good (enough) mother mean, and why is it important to explore this question regarding disabled women? The term "good enough mother/parent" originally comes from the British psychoanalyst Winnicott from his 1971 work *Playing and Reality*. In it, he writes that a good enough mother submits to her infant's needs to meet them fully (Winnicott, 2005). However, other researchers (Daniels, 2019, 2020; Lendvai, 2022) suggest being a 'good mother' is no longer enough – women must also excel in this area. Society is highly critical of the issue of motherhood. Even non-disabled women are watched with a wary eye and must meet demands that very few can meet. In the conservative Hungarian society, women are required to work and be able to take care of their children. Socialism created the image of working women who were equal to their male counterparts, but this did not necessarily include disabled women (Berzsenyi & Békefi, 2024). Modern society creates demands that are not realistic, not even for able-bodied women. One such demand is that the woman should always be physically fit, have endless energy, and be independent and mentally stable. Daniels (2019) describes the right mother with these qualities. However, non-disabled women cannot always fully meet these demands in all circumstances. Disabled women usually do not have the chance to meet all of these requirements. In addition to all these expected qualities, the traits that help to create a secure attachment in the mother-child relationship are

overshadowed. Such qualities include kindness, love, acceptance, and caring. These help to create emotional safety in the child and can be possessed by any mother, regardless of whether she can meet the above requirements.

Mainstream society tends to think that people with disabilities should not have children, or if they do, it is not for the joy of having children but to be helped by the non-disabled child (Prónay & Gombás, 2021; Lendvai, 2022; Hoffmann et al., 2023). There is also a fear of passing on disability. These can be traced back to ableism, which in this case means expecting the disabled person to behave in a certain way (Campbell, 2009). Also, there is eugenics2 underneath, which can then lead to forced abortion in case of both disabled and non-disabled women (Sándor, 2019; Katona et al., 2016; Katona & Szücs, 2017; Katona & Szücs, 2018; Katona & Szücs, 2019; Hernádi & Kunt, 2016, 2017, 2018, 2019).

2.2. Visually impaired mothers

There is a large body of research in the literature that explores the experiences of visually impaired mothers from a psychological, anthropological, or disability studies perspective, typically using qualitative methods (see Shackelford, 2004; Rosenblum et al., 2009; Molden, 2014; Moghadam et al., 2017; Lendvai, 2019, 2022; Lendvai & Nguyen Luu, 2019, 2022; Hankó et al., 2022; Commodari et al., 2022).

Molden (2014) applies both a psychological and a disability studies approach in her research. While her method of exploring the experiences of visually impaired mothers is psychological, her conclusions show a disability studies approach. She formulates two paradoxes that visually impaired mothers face in raising children: visibility and independence. The visibility paradox describes the phenomenon where mothers are both visible when criticized and invisible when they need support. In this context, the independence paradox describes the phenomenon where a woman does not dare to ask for help because it proves her incompetency. The research of Lendvai (2019), Lendvai & Nguyen Luu (2019), and Lendvai (2022) also supports the idea that visually impaired women are questioned in their ability to perform gender roles, including motherhood. Lendvai & Nguyen Luu (2019) also show how visually impaired women conceptualize fears about motherhood and how they cope with these fears. Several studies show that visually impaired women also experience situations in their health care that question their ability to parent. In some cases, they are even encouraged to abort their fetus (Schackelford, 2004; Lendvai & Nguyen Luu, 2019). Rosenblum et al. (2009) and Moghadam et al. (2017), Commodari et al. (2022) detail the difficulties that visually impaired mothers face, such as the difficulty of constantly monitoring the child, interpreting the child's visual cues, difficulty in visual communication, and participating in activities that require vision (e.g., drawing). This also reveals how they cope with these difficulties, which demonstrates that the ableist attitude towards them that they are not fit to raise children is unsubstantiated. They can bring up their children, although they undoubtedly do so in alternative ways. This is supported by the two studies by Hankó et al. (2022), who conducted a comparative study on sighted and visually impaired mothers' experiences of motherhood. The

2 According to Wilson's (2024) entry in the *Britannica, eugenics was a movement that aimed to "ennoble" the human race by passing on traits that were considered desirable by eliminating undesirable traits.*

results show that the experiences of the two groups are very similar. According to Lendvai & Nguyen Luu (2019), visually impaired mothers do not perceive significant differences between groups, and the authors even point out that they believe that visually impaired women are less afraid of taking on infant care tasks than sighted women, since, e.g., they attended the *Special Techniques of Infant Care for visually impaired Persons* rehabilitation course which gave them knowledge and confidence (Tolnayné Csattos, 2011; Tolnayné et al., 2015).

3. Methods

3.1. The combination of qualitative methods: Grounded Theory and narrative interview

Combining qualitative methods within qualitative research is rare, but we can see some examples. Researchers tend to turn to this solution when they want to explore layers of reality that other traditional methods cannot access, or when they want to discover different perspectives of reality (Lal et al., 2012; Morse, 2009). This study combined narrative life history (NLH) and Grounded Theory (GT). The purpose of combining these two methods was to explore a dimension of the lives of women with visual impairment that is otherwise difficult to access or that we would not consider as a perspective. We combined the strengths of the two methods. Rosenthal's (1993) approach to narrative interviewing gives interviewees space to express their perspectives and to tell their narratives. Meanwhile, GT allows us to reflect on our work and the literature (Mitev, 2015). GT's coding method allows us to work without an already existing framework and also enables us to construct our own theoretical framework (Corbin & Strauss, 2015). While narrative interviews focus on what narrators say and, therefore, put them into the foreground, GT provides the opportunity to construct a theoretical framework (Bruck, 2005; Morse, 2009, 2010). Combining these two methods provides the opportunity to frame narratives and compare them to one another. Rékasi et al. (2024) have conducted research using this combination of methods focusing on the school path of women with visual impairment.

Our research focuses on the following question: What characterises visually impaired mothers' experience and lived experiences of motherhood? By combining these methods, we could emphasize the individuals' narratives of motherhood and frame them simultaneously. This way, we could also highlight the common points of the experiences.

3.2. Data collection and sample size

The snowball method was used to recruit the interviewees. We knew two of the women personally. One of them recommended another interviewee who referred us to another woman. We read about the fifth woman in an internet article where her full name was published. We contacted her on Facebook. This method is beneficial when researchers try to reach groups that are hard to reach anyways (e.g., homeless

people) or when a certain level of trust is needed towards the interviewer, like in our case (Babbie, 2019).

In interview-based qualitative studies, the size of the research sample can determine the reliability of the research. It is often stated that these studies should continue to take interviews until they reach saturation (Hennick et al., 2017; Young & Casey, 2019). The saturation can indicate that we have conducted a reliable study, and our results can be interpreted generally in the given social group (Hennick et al., 2017). However, according to meta-analyses, saturation is vaguely defined in the research methodological literature; therefore, it is difficult to determine a sample size that brings us 100% saturation (Morse, 1995; Guest et al., 2006; Hennick et al., 2017; Young & Casey, 2019). However, saturation is generally determined when data starts to repeat itself, meaning that interviewees do not say anything new that has not been said by the interviewees before (Young & Casey, 2019; Tight, 2023). According to Young & Casey's (2019) meta-analysis, saturation can also be achieved with a small sample size. They concluded that even 9 participants can bring saturation. In disability research, we encounter studies with a low sample size, even with only one participant. Hernádi (2014) had only 10 participants in her study, but Kunt (2019) worked with only one interviewee as the social group she was writing about was small. Commodari et al. (2022) also worked with a few participants in their study of visually impaired women. Only 15 women participated in their study.

In our case, the small sample can be explained from two points of view. The population is small (independent visually impaired women with children under the age of 14). The topic where they had to talk about their family lives and difficulties is sensitive. Because they started their own family, they went against society's expectations, and this is a hard topic to talk about, even if they are happy with their decisions. So, this is a hard-to-reach research topic where any results contribute to our knowledge.

3.3. A brief introduction of the interviewees and description of the interview situations

We interviewed five visually impaired women: Bea (32), Janka (40), Vera (45), Edit (38), and Nóri (32). They all had at least one child under the age of 14. At the time of the interview Bea was the mother of a baby and a toddler, Janka's child was in elementary school,[3] Vera's older child was in middle school,[4] her younger was in elementary school, and Edit had two preschoolers.[5,6] We anonymized the interviews until the interviewees were not recognizable. We chose pseudonyms instead of just numbers or letters because they make them less objectified.

The presented results are part of the first author's doctoral project. This also means that these are only partial results and will be complemented in later stages.

3 Ages between 5-10 years.
4 Ages between 11-13 years
5 In order to protect the anonymity of the interviewees, the exact age of the children is not disclosed, only the age group to which they belong. For this purpose, the age groups used in the American Occitan Order are adapted.
6 Ages between 2-5 years.

Janka was 40 years old at the time of the interview. She is the mother of one child, divorced from the child's father. They raise their child in joint custody. She lives in Budapest. She works and has several degrees. She is fluent in several languages. She self-identifies as blind.

At the time of the interview, Vera was 45 years old. She is married and the mother of two children. She lives with her family in Budapest. She has several college degrees and other professional qualifications. She self-identifies as partially sighted.

Bea was 32 years old at the time of the interview. She is a mother of two and lives in Budapest with her family. She holds several university degrees and is fluent in foreign languages. She considers herself blind.

Nóri was 32 years old at the time of the interview. She is the mother of one child. She lives with her husband and child in a town near Budapest. She has several university degrees and speaks foreign languages. She considers herself someone with low vision.

Edit is a single mother of two children, 38 years old at the time of the interview. She lives with her children in Budapest. She describes herself as 'non-sighted' because the term 'blind' evokes negative feelings.

It is important to notice that four of the five women are highly qualified, have more than one university or college degree, and are fluent in other languages. The only exception is Edit, who might not have a university degree but is also very self-sufficient in different areas of life and has a white-collar job. This also supports the theory that visually impaired women who are educated and have good jobs are the most likely to have children.

In the case of Bea, Janka, Nóri, and Edit, the interviewer met them in their homes, while Vera, at her request, was met in the quiet, calm office. For each interview, the interviewer explained the methodology and the purpose of the research, read out the research ethics consent form, and obtained the signatures of the participants. A typed form was provided for all and sent electronically to all interviewees. All interviewees can sign with some assistive device (magnifying glass, signature frame). In all cases, the interviewer informed the participants that the interview would be audio-recorded, from which verbatim transcripts would be taken with the involvement of a typist who signed a confidentiality agreement. The researcher also informed the participants that the interview could be interrupted at any time without giving any reason, that a break could be taken if required, and that consent could be withdrawn. The subjects were also informed that the researcher would take notes in addition to the audio recording and that he would include them in the research diary.

4. Results

We conducted our analysis with MAXQDA 2022. This software is very suitable for GT as it has all the features needed for a complex analysis (Rädiker, 2023). In every interview, motherhood was one of the significant codes regarding their life stories. Motherhood looks different for every one of them. Their focus is different, whether they foreground their difficulties or emphasize how they cope with them, but we can certainly identify similarities in their narratives. In the following paragraphs, we introduce these common areas. We quote parts of the interviews that are good

examples of the highlighted topic, but due to space limitations, we do not include every relevant quote from every interview. However, we find it essential to include the quotes despite the space limits, because we want to give a voice to these women.

4.1. Passing on disability

The heredity of their eye condition or their spouse's eye condition was a significant question in Vera's, Janka's, and Nóri's interviews. Janka does not know the genetic background of her eye disease. Her ex-husband is also visually impaired, so they thought it would be a good idea to visit a genetic specialist. However, they could not determine their genetic background and could not provide helpful advice. Although Vera exactly knows her eye disease, heritability cannot be excluded as she saw an example among her friends with the same condition to have children with their parents' eye disease. Before she had her first child, she looked into the current medical research, which also supported her theory about this. Nóri was born prematurely, and she lost her vision due to Retinopathy of Prematurity (ROP), which is not a genetic condition. Her husband, on the other hand, suffers from an eye disease that has a very high heritability. So, they are concerned about having a second child. Nóri and her husband were advised to test their fetus for the genetic disease, but the test had risks and the results would not influence their decision about keeping it or not. According to Hernádi & Kunt (2018), women who receive positive genetic test results in a fetal stage are often advised to abort the fetus.

> *Oh, and what is so important from our point of view in terms of having a baby or having children is that my husband has a hereditary eye disease. [...] So the first months of the baby were filled with examinations and genetic tests, which could have been done even in fetal age, but because there was a risk of miscarriage and it did not really affect us regarding keeping him, whether he would be visually impaired or not, so these tests were done only after his birth, but thank God he did not inherit, he is completely healthy. However, we want to have at least one more baby, and again, there is a risk that they will inherit it, so it's a bit of a specific issue for us.* (Nóri)

Edit also has an eye disease with a high chance of heritability, but her case is unique as her pregnancy was unplanned. She was aware of her condition but still decided to keep the pregnancy. She was happy about it. She stayed with her ex-partner during the pregnancy, they even moved in together, but she terminated the relationship not long after the birth. They have joint custody, but Edit is the primary caretaker.

> *And then we wanted to end it anyway; we wanted to end this whole story with my ex, but then it just struck me that I wasn't feeling well or I was tired, because the fact that I was late wasn't strange to me... I didn't think it was a pregnancy because I had been missing my period for a long time. I just felt really tired. Then I wrote to him to do a little calculation together because I felt so suspicious about the whole situation happening to me. And then I did, and then I took a test, and then it was positive. And then I told him that this was the case, and I was 33 years old. So, at 33, you don't go for an abortion, and for us, our financial situation and our whole life space allowed us to have children.* (Edit)

Bea was the only one who did not express concern regarding this topic, as she also has ROP, and her husband is sighted. Regardless of all the concerns, they all thought life as a visually impaired person could be very good, so they should take their chances and try for a baby. Janka's words are very touching and realistic.

> *…we said yes, we both agree that we both want to do whatever we can to make sure that our child can see, so that's why we went to the geneticists, but when we checked it out, we were like, okay, there's still no guarantee, we also agreed that we definitely want a child, and that if it is a visually impaired child, we already know that even though we have to run a hundred laps more in everything, as my friend said, but that it is still possible to live very happily as a visually impaired person, and that we will teach our child how to do this.* (Janka)

4.2. Pregnancy and childbirth

Although pregnancy and childbirth were only emphasized in the narratives of Bea and Nóri, it is essential to discuss this topic because access to reproductive health services is a human right. Even non-disabled women with uncomplicated pregnancies and childbirth experience some form of sexism or obstetric violence. Women often have to put up with disrespectful comments from the health staff, are forced to take medications they do not want, or go under unconsented non-life-saving procedures (Diaz-Tello, 2016; Kertész & Nyúl, 2022; Sadler et al., 2016). In addition to that, disabled women report verbal and physical abuse, discrimination, neglect, abandonment, and violation of privacy (Wudneh et al., 2022). Deaf people can experience difficulties in communication (lack of interpreter), and visually impaired women miss reasonable accommodation during OBGYN visits and in the delivery room (YupanquiConcha et al., 2024).

Nóri expressed her fears and anxiety about the delivery and what she could experience as a visually impaired woman: whether she would have the right kind of help, whether she would be able to have her trusted midwife in the delivery room, whether the doctors were going to be nice to her, would she be able to advocate for herself or communicate her needs, whether her privacy would be respected. Her childbirth turned out to be all right, but her anxiety itself says a lot.

> *And just that you could not choose a doctor anymore. My midwife could have been there by some miracle, so I found out at the last moment. However, I was afraid that if I didn't have a midwife or a doctor, the doctor on call would see me. If he would know how to help me, because obviously the thought of random people coming and looking at me and touching me, and that I wouldn't know what was happening, was killing me. But the midwife was there the whole time, so she could help me. And that's why... So, I was lucky. But it was a big fear for me that I wouldn't be in a position to communicate what my needs were and whether I was going to get out of it. Because obviously, in childbirth it is very important what kind of mental state you are in, what kind of hormones are released, and I was afraid of being stressed by the medical authority, about what I should do there and how I should do it, so whether I could represent my needs there, but luckily it worked out well.* (Nóri)

Bea's pregnancy was complicated, and she had to have her first child by C-section. In such cases, the OBGYN often recommends that the second child is also delivered by C-section to avoid possible complications. This was Bea's case, too, but she had read books about the topic, even enrolled in a course to be prepared, and she was determined to have a natural childbirth. However, she did not go into labor by the due date, so her doctor again recommended a C-section. However, due to the COVID-19 measures introduced, Bea's preferred "gentle C-section" was not feasible, and her husband could not be in the operating theatre with her, so she stuck to her decision. Her narrative of this gives us a very realistic insight.

> *And of course, I didn't go into labor until the term, and then my doctor said that I would have to sign for the cesarean and then he saw that I wasn't happy about it, and then he said »But we can't force it!«, and that I could sign that I refused at my own risk. I said that I would sign it, but I would sleep on it. I signed it, but they told me to say in advance because then they wouldn't prepare the operating theatre, and I said I would tell them And it was Monday or whatever it was? Yes, it was Monday, Thursday the 26th... (counts) Yes, it was supposed to be the 23rd, and then, okay, I signed to do it. So, »How long do we wait? Is it OK if we wait until Thursday?«, OK, I say Thursday, so then Thursday is the day of the cesarean if it doesn't start by then. [...] we had to go every day, and then the doctor said, »Well, shall we do it? Surgery tomorrow?« but all the tests were perfect. Well, I said, sorry, if all the tests are perfect, then I won't do it, and then it turned out that because of Covid, it was not possible to have such a gentle cesarean, but they would take the baby away, my husband wouldn't see,it so I said, I won't do it. So, we decided to wait a week until the following Monday, and if it hadn't started by then, then a cesarean. And then I did go into labor, actually at the crack of dawn on Thursday.* (Bea)

4.3. Infant care and parenting

Visually impaired mothers are often questioned about their ability to care for their babies. While they may have to resort to alternative solutions in some situations, that does not mean that it is worse if it does not harm the child. Vera, who is partially sighted, has many useful tricks and tips, both by her invention and by hearing about them from other visually impaired mothers.

> *The medicine with a spoon, which I don't give them with a spoon, but with a syringe, because that way, it can be measured out and not poured into the child's mouth. The little things, for example, that I bought my children a dog collar with lights, and, let's say, at dusk we went to the playground and out on the motorbike with a dog collar with lights, because I could see the child then, but not without them.* (Vera)

The dog collar might sound drastic, but Vera has difficulty seeing at dusk, so the neon lights give her and her children the security they all need. A collar, in this case, serves as a visibility alternative that can be attached to any body part or piece of clothing.

Edit's children experienced a serious illness early in their lives, which posed a serious challenge to their blind mother. A big portion of Edit's narrative was about

their experiences in hospitals and doctors' offices, where she was constantly made to feel that she could not be competent in certain situations.

> *The doctor was horrible, otherwise humiliating, and I can only use that word to describe them. They forced us into a situation where I could not be alone with my child during treatment. My friend, for example, never had this problem. So, she fought, they got through it, she had enough, but they were alone until then. The medical team at the time made that possible and there was never a problem. And then they would only let us go there with help. This meant that we had to arrange for someone, either paid [...] or volunteer, to spend the nights with us in the hospital.* (Edit)

Edit had several stories about the child hospitals where her children were treated and about the different attitudes of healthcare workers regarding her visual impairment in this situation. Although in certain situations she needs help from a sighted person (e.g., checking if there is blood in the baby's diaper after treatment) her general ability to be a mother should not be questioned based on her disability in this extremely difficult situation.

Visually impaired pregnant women can ask for support in the frames of rehabilitation. The Hungarian Institute for the Blind has a special infant care rehabilitation module called *Special Techniques of Infant Care for visually impaired Persons* (Tolnayné Csattos, 2011; Tolnayné Csattos et al., 2015). The module is specifically made for visually impaired pregnant women, but their partners can also participate, especially if they are also visually impaired. This is a great opportunity for first-time mothers because a specially trained rehabilitation teacher (often a visually impaired mother herself) helps them with the special techniques and gives them advice. Nóri and Bea both enrolled in this module and spoke highly of it as it gave them knowledge and the confidence they needed to become the best caregivers of their children.

> *Then we had a nicely built curriculum, so we really went around everything: the diapering and the breastfeeding stuff. [...] They showed me what to look out for, so to say, blindly, it was very good, it gave me confidence, so it wasn't that I didn't know, it was just that we went through it again, like when you read the material again before an exam, it was very good, I really needed it, so really. So, everything, even feeding, complementary feeding, dosage of medication, what to pay attention to, so it's very complex.* (Bea)

Nóri appreciated the fact that the rehabilitation teacher offered to support her after the course as a reassurance.

> *So it wasn't that much time, but there's a lady there that I've been in touch with ever since, if I needed any help with specific issues, she'd be there. I didn't have to call her, thank God, we met while I was pregnant twice or three times, and she showed me the basics, diapering, dressing, one or two of those tricks.* (Nóri)

Janka did not take this module as she could lean on the advice of her friends who already had children. Peer support is crucial as the women have examples ahead of them and can share their difficulties with peers who understand them.

> *And it took quite a bit of awareness, obviously, to prepare for what's going to happen when this baby gets here, so we asked other visually impaired parents for advice. I learned how to change diapers from one of my good friends. And we learned how to wrap a baby carrier from another friend, and then we didn't wear baby carriers for a long time because I think it's a hassle, but it was really cool to actually get advice from other parents.* (Janka)

Vera highlighted that her smartphone is a great ally in certain everyday parenting situations, such as when she has to read a note on the school bulletin board or read labels on grocery store items.

> *…now with modern technology, »Oh, if you could take a picture of it and send it to me, that would be great!«, e.g., class photo posted, and then you can choose which one you want to order, well, I don't stand a chance, but now it works, it's either him or me taking the photo, now that I have a smartphone, I can zoom in very well, so you can use those now, but before, until I had these possibilities, back in my daughter's time, well, it was on the bulletin board, but I couldn't do anything with it…* (Vera)

In all of the narratives, the help from family and friends is crucial to parenting. This is especially true of Edit, a single mother who really needs her friends' support, but Nóri, Vera, Bea, and Janka also mentioned they have support from their parents, grandparents, and friends. Edit had numerous supporters who helped her during the children's sick periods. Still, she highlighted a particular connection with a couple who are a significant part of their lives and support her and her children in many ways. They have been in their lives since the children were babies. This quote from Edit is just one example of the support they receive from them, especially from the husband.

> *And then my friend does a lot for us—so much more than he should or could because if the girls are sick, he comes here on Tuesdays after work and is with me until 11 o'clock. It's very good in many ways. On the one hand, he helps us with what we really need, he's here to take the girls' temperature, make tea, or, let's say, obviously he is just here with us.* (Edit)

5. Conclusions

Our research is not representative because of the small number of participants – which is due to the fact that these are preliminary results from the first author's doctoral project – but it tells us a lot about the experience and perceptions of visually impaired women, about having children, and gives us insights into the difficulties they face and the resources they have in order to be successful parents. Although the mothers in our research face difficulties, there are also supportive factors in their lives that serve as resources. The fear of passing on the disability is a very understandable and rational emotion, as certain eye conditions can be fatal (e.g., neuroblastoma) or count as a chronic illness (e.g., glaucoma). Regardless of the cause, visual impairment is a factor that affects the individual's life quality (e.g., it affects their orientation and mobility skills or limits the jobs they can take), so it is understandable if someone considers it before having children. The interviewees

considered the disadvantages and concluded that their lives were good and that they could teach their visually impaired children how to live life as such. This counts as a difficulty because it affects mental health, and other women who are sighted (and otherwise able-bodied) do not have to think about this. It is also worth noting that in the case of disabled women, becoming a mother can be a "deviance" in the eye of society and counts as a rebellion against norms (Lappeteläinen et al., 2016, 2018).

Although four of the five women in our study faced the possibility to pass the eye condition to their children, this has not influenced their decision about having children or keeping the fetus. An exciting line of research is the question of the role of the fear of passing on a disability in the decisions of visually impaired women who are consciously childless. The fact that someone knows the cause of their visual impairment can play a significant role in their decision to have children, as we can see in Bea's case. Although the other women also decided to bring children into the world despite their awareness of the possibility of heredity or the uncertainty of it, their cases show us that the evolution of genetic research regarding this topic is needed. This is not to eliminate blindness but to give the possibility of informed decision-making for those with visual impairment.

In this study, we have only touched on the topic of obstetric violence, as pregnancy and childbirth were not a primary focus for all the narrators. Where the narrator did not talk about it herself, we have been sensitive, not forcing the recollection of these memories. However, it is essential to talk about the subject, which is why we have included it in our analysis, because many disabled and non-disabled women experience it. Both Nóri and Bea had to be well prepared for their delivery to get everything they needed and not be forced into any situations they did not want to be in. Although obstetric violence cannot be avoided and it is not under the women's control, visually impaired women must be prepared mentally to be able to react to situations in the delivery room. The experience of obstetric violence and sexism in the delivery room as a visually impaired woman points us in the direction of qualitative research where the visually impaired mothers could talk about their experiences regarding this topic.

All interviewees reported experiencing difficulties in infant care and parenting, but they also had resources to avoid or overcome them. Regarding the difficulties, it is important to keep in mind that not every difficulty is caused by visual impairment itself or the ableism toward visually impaired people (e.g., it can be caused by a personality trait). It is also important to highlight that today's nuclear family model also poses enormous challenges for every family where everything is expected from the parents, especially from the mothers: caring for their children 24 hours a day, running a household, winning bread, etc. This puts women in a challenging position because they often have to be mothers and breadwinners. In extended families where multiple generations live together, household chores such as childcare-related tasks are divided, which takes off responsibility of the mothers' shoulders without questioning her ability to be a mother. Although this is not specific to visual impairment, it weighs more on families with visually impaired mothers, and they could benefit from the multigenerational model. Our study shows that the difficulties caused by visual impairment can be solved if someone is resourceful and has a great family and friends as a support system. Alternative solutions can be learned in the *Special Techniques of Infant Care for visually impaired persons* rehabilitation module,

which is entirely free of charge for visually impaired parents. Taking the module can eliminate the anxiety of first-time mothers regarding their ability to provide child care and give them confidence in their actions. Having other visually impaired parents as friends is also a great resource that can give good examples and opportunities to exchange experiences and fears. This informal way of exchanging experiences is as important as having a particular model as an opportunity.

As we can see, visual impairment cannot be grounds for exclusion from the experience of motherhood. Motherhood might look different for visually impaired women than it looks to other women, as they have to turn to alternative solutions in certain situations. However, as long as the children are safe and the family is happy, these alternatives are just another way to be a mother.

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